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ABSTRACT

Being diagnosed with a serious illness is a major crisis to face for both the individual with the illness and the loved ones involved. To better prepare patients and their families in the adjustment to the impact of illness, it is essential to teach them the various emotional responses commonly experienced and effective coping skills. Helping professionals need to be aware of the grief reactions experienced when a life-threatening diagnosis is made. Helping the patient and the family to identify the emotions and the fears involved reduces anxiety and feelings of helplessness. Processing feelings of shock, anxiety, anger, depression, guilt and shame and learning ways to adjust to the myriad of changes that are imposed with an illness can enable patients and their families to deal more effectively with this crisis. More importantly, this process helps the patient to adapt and to move toward the establishment of a new identity and awareness that involves more than just physical attributes and abilities. When involved with families who are confronted with a serious illness, it is important that helping professionals respect whatever emotional reaction is being expressed. The role of the helping professional is to offer compassion, understanding, and an opportunity for companionship to the family that struggles with this crisis. (Author/ABL)

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Understanding the Emotional Impact of a Serious Illness

By Nancy Groves, M.S.W.

Being diagnosed with a serious illness is a major crisis to face for both the individual with the illness and the loved ones involved. Understanding and integrating the full impact of the disease on one's life are difficult tasks. To better prepare patients and their families in the adjustment to the impact of illness, it is essential to teach them the various emotional responses commonly experienced and effective coping skills.

Helping professionals need to be aware of the grief reactions experienced when a life-threatening diagnosis is made. Helping the patient and the family identify the emotions and the fears involved reduces anxiety and feelings of helplessness. Processing feelings of shock, anxiety, anger, depression, guilt and shame and learning ways to adjust to the myriad of changes that are imposed with an illness can enable patients and their families to deal more effectively with this crisis. More importantly, this process helps the patient adapt and move toward the establishment of a new identity and awareness that involves more than just physical attributes and abilities.

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Understanding the Emotional Impact of a Serious Illness
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Facing a chronic or life-threatening disease presents a crisis situation for both the individual facing the illness and the family or loved ones involved. For the patient, there is the crisis of facing the unknown, with the possibility of impending death. For the family, there are constant changes to its homeostasis which impact on each family member in a unique way. Levels of anxiety increase that demand effective intervention skills so that the patient and family can respond with coping abilities commensurate with the challenge ahead of them.

As helping professionals, we need to be aware of the physical, psychological, and social impact of disease. We need to understand the physical progression of the disease, what treatments may be required and what effect these may have on the patient and family. Linking the family to medical professionals to convey this information is crucial and can effectively reduce some of the anxiety felt when an illness is first diagnosed. Knowing what to expect reduces the feelings of helplessness and fosters a sense of control for families.

In order to effectively assist patients and their families, it is essential for helping professionals to become aware of the various emotional reactions commonly experienced when a serious illness has been diagnosed. The patient's and the family's emotional reactions can include anxiety, anger, depression, guilt and shame. Identifying these reactions and understanding the unique meaning each reaction has to the person experiencing the emotional response are essential components in helping the person and family cope with the crisis they must face.

Anxiety is a common reaction for anyone trying to integrate the knowledge of being afflicted with a serious illness. Anxiety can become overwhelming if it is not broken down into its component parts or fears. Helping a patient identify those fears is a first step in making the anxiety more manageable. Some fears which frequently surface can include fear of the unknown, fear of loneliness, fear of loss of self-control, fear of loss of body and abilities and fear of suffering.

Fear of the unknown is a common fear for many of us. In order to reduce some of the unknowns associated with illness, it is helpful to distinguish with the patient those questions that can be answered from questions where only opinions can be shared. Questions related to the specifics of the disease, about the course of the disease and treatment procedures can be answered. Questions related to religious and philosophical concerns require the sharing of beliefs and opinions. Linking the patient with an appropriate resource person in both areas of questioning can eliminate some of the unknowns and can be therapeutically helpful in reducing some of the anxiety associated with this fear.

Fear of loneliness is experienced whenever people are afraid. In sickness, people tend to be isolated, physically and emotionally, from others. Some people find it too painful to offer their presence to someone who is ill. Being reminded of their own mortality and vulnerability to illness can create anxiety that makes isolating the patient a more comfortable response. For the patient, however, this is the time when the comfort of loving others is essential. Encouraging family members to be present to the ill person is not only a loving response, but also one that promotes emotional health and inner peace for the patient.

Another fear that causes much anxiety is related to the fear of loss of self-control. Our culture values self-sufficiency and independence. To be afflicted with an illness that reduces abilities and causes increasing dependence can be a humiliating experience. Enabling the patient to retain control over as many areas of possible is one way to reduce some of the anxiety associated with this fear. Families need to be taught to encourage the patient to do whatever is possible within the capabilities the illness imposes. Families who take over and do everything for patients not only increase the anxiety, but also overtax themselves.

A related fear concerns the loss of body and resulting disabilities or disfigurement. Because so much of our self-image is based upon our physical characteristics, a serious injury to our sense of self is experienced when an illness progresses. The changes in abilities and appearance can result in feelings of shame, inadequacy, guilt and worthlessness. Patients need to identify the losses they are feeling and to grieve those losses. Families can be a support in this by simply listening and validating the emotions expressed. Encouraging the patient to engage in a life review process can also help to reaffirm an identity and can expand the sense of self to go beyond the physical attributes.

The last fear that can cause anxiety is the fear of suffering and pain. For the person with a chronic or life-threatening illness, there is not the hope of relief from illness. Physical and mental pain can impede a person's ability to effectively respond to illness. Therefore, it is important to assist patients in ways that will reduce the pain they are experiencing. The approaches used can include medications,

but should not be limited to this. Other effective interventions can include massage, meditation, imagery, biofeedback and the loving presence of others.

Anxiety that is experienced by the family is related to the sense of helplessness they feel when a loved one is ill, the demands of care that the illness can require and the sense of loss due to family role changes.

Feelings of helplessness can often overwhelm families because they are constantly exposed to the myriad of changes, physical separations and sufferings that come with illness. Loved ones struggle with the need to do something, when oftentimes, there is little that can be done to change the reality of the situation. Teaching families the importance of being, of offering their presence, is one way to reduce some of the feelings of helplessness. Giving families sufficient understanding of the disease and what to expect can also provide a sense of control for families and reduce the anxiety.

Feelings of anxiety are also experienced due to the many responsibilities given to the families who are caring for the person who is ill. Teaching the family proper care procedures and linking them to community resources can relieve some of this anxiety. Supporting any kind of family involvement in the care plan is also helpful. Encouraging time out for emotional and physical replenishment is essential for families.

When a loved one has been diagnosed with a serious illness, the family begins a grieving process over the many losses they will experience. The family may lose certain roles or behaviors that kept the family together. The patient, too, loses his or her place within

the family, and the family struggles to re-establish itself with a new identity. Encouraging the grief process to proceed helps the family and the patient work through the feelings and to reinvest the energy in ways that strengthen the family unit.

There are other emotional reactions experienced in addition to anxiety. Depression is a common response to illness and can be observed in both the patient and the family. For the patient, depression is a common reaction to the anticipation of the many losses that will be experienced. For those with a terminal illness, the threat of impending death is a reality that triggers depression. Allowing people to express sorrow and regrets can release some of the depression and make it less overwhelming. Minimizing or offering unfounded hope only suppress the emotions being shared and result in feelings of isolation.

For the family, depression can be immobilizing and may result in the family distancing themselves, physically and/or emotionally from the patient. One way to assist the family is to place the sadness within a context of meaning. Helping the family understand that their depression reflects the depth of their love for the person who is ill can provide emotional relief. The family also needs to learn that the expression of their sadness will not result in losing control, but will provide a release and will enable them to maintain closeness at a time when it is needed most. It is important to convey a sense of hope for the time in the future when the intensity of their depression will decrease. Encouraging family interactions so that pleasures can still be experienced also reduces some of the depression felt.

Anger and hostility are emotional reactions commonly experienced by the patient and the family. The patient often

responds with anger because of the many changes the illness imposes on his body and life over which there is little control. Being deprived of a future with good health, having to suffer pain, and being responded to differently by loved ones all serve to increase anger. Often, the anger is displaced on anyone or anything else that is available, including family members, friends, and the medical profession. Anger is usually a mask for the more painful feelings of grief and anxiety. The most effective way to respond to the anger being expressed is with acceptance and with non-judgmental responses. Anger is a normal and understandable reaction to illness. If it can be freely expressed, without guilt, it will dissipate in time.

Families also experience anger, although most families have difficulty admitting and accepting this emotion. Anger is usually felt as a result of the feelings of helplessness and hopelessness, and the emotional and financial drain that are realistic consequences of serious illnesses. Using family conferences where differences can be aired and anger expressed can help process this emotion. Encouraging the family to use acceptable physical outlets can also effectively reduce and release the anger.

Guilt is felt by patients for many reasons. People often experience guilt when faced with a serious illness, for they believe the illness is a form of retribution for past offenses. Feeling envious or jealous that others are healthy can produce guilt. The normal feelings of grief, such as crying, can also produce feelings of guilt. It is important to help the patient identify irrational beliefs where guilt is unfounded and to normalize the guilt as a common reaction. Assisting the person to forgive himself for behaviors that may have caused harm or offended can also reduce feelings of guilt.

Families experience guilt due to the expression of "unacceptable" feelings of anger and resentment, due to a feeling of being

being responsible for the illness, a feeling of not having adequately protected the person or simply because they will survive. It is helpful to normalize the guilt, to see it as a common reaction and to encourage self-forgiveness where appropriate. Encouraging family involvement in the patient care plan can also reduce feelings of guilt. Families need time for emotional and social replenishment to reduce the feelings of resentment, anger and guilt.

If we are involved with families who are confronted with a serious illness, it is important that we respect whatever emotional reaction is being expressed. Many times, it is our fear that causes frustration and an eagerness to move someone to a different emotional state. We must realize that the emotional reaction serves the needs of the patient or the family at that moment and is crucial to their emotional survival. Our role is to offer compassion, understanding and an opportunity for companionship to the family that struggles with this crisis. Providing unconditional acceptance and support, and offering honesty, respect and comfort are the gifts we can give.

(To help families and patients, a short book of poetic prose, Living With Illness, has been used effectively. It sensitizes the family to issues faced by the patient and provides an avenue for communication within the family. It can be purchased directly from the author for $5.95. N. Groves, 4469 Brandywyne, Troy, MI 48098)